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Roll-Up Report of Prevention & Community-Based Support Regional Projects

Funded/In Progress
2000-2001

Canada

Roll-Up Report
of
Prevention & Community-Based Support
Regional Projects

Funded/In Progress
2000-2001

Prepared for:
Hepatitis C Prevention, Support and Research Program
Community Acquired Infections Division
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1. Introduction

The purpose of this report is to provide an overview of projects funded during fiscal year 2000-2001 by the Hepatitis C Prevention, Support and Research Program ("the Program"). The five-year Program supports local, regional and national organizations in their efforts to address hepatitis C collaboratively at the community level. This roll-up report is the second of its kind to be issued since the inception of project funding in fiscal year 1999-2000.

The report has two main objectives:

- to fulfill the Hepatitis C Program's commitment to transparency and public accountability for the effective use of dedicated resources;
- to inform and help guide the activities of the Program.

The focus of this report is on project results – intended and unintended – and on key lessons derived from the project experience. With an eye to best practice, the report identifies processes and products deemed by project organizers to have "worked". It also reviews issues arising from the year's projects with implications for the future. As well, it considers the accomplishments of the second funding year in the context of the Program's goals and objectives.

Certain factors have limited the ability of this roll-up report to provide an entirely accurate picture of project experience in the period under review. In theory, the report covers all community-based projects funded between April 1, 2000 and March 31, 2001. In practice, however, it is based on project reports and documents received on or before February 15, 2002. (Materials arriving after the deadline date were used for statistical purposes only.)

Most of the outcome-related information was based on the observations of staff/volunteers, often without the "ideal" back-up or proof. While front line personnel are well placed to notice changes in behaviours, attitudes, self-confidence and so forth, and to provide qualitative information on these, their reports may not on their own be considered objective.

However, taking baseline measurements, conducting valid surveys and implementing similar evaluation techniques were beyond the capacity (and resources) of most project groups. Their conclusions and observations stand to be tested over time, as results accumulate and reporting processes grow more rigorous. At this stage in the Program, however, discerning key themes and trends requires a close reading of the project "results" and reports collectively. Over time, more critical analysis of project evaluation/performance reports will be possible.

The discussion in this report covers *planned* as well as *actual* project results. This is because a considerable number of projects (both completed and incomplete) did not submit their reports by the deadline date, making it necessary to consult various "pre-project" documents, such as funding application forms and project summaries, for information on

anticipated outputs and outcomes. It should also be noted that, among those projects that did submit reports, there were wide variations in the reporting formats adopted[1], the level of detail supplied, the interpretations given to key terms and – where evaluation information was provided – the evaluation approaches taken.

Project groups faced many other evaluation challenges. For example, although some of the results they achieved were quite tangible (e.g., outputs such as training sessions, pamphlets, plays, etc), the effectiveness of these outputs may remain in question. Do they actually work? And, if they appear to work, is the result necessarily attributable to the particular output? When many influences are at play – for example, press articles, radio call-in shows, friends sharing knowledge – is there any valid basis for attributing positive results solely to project activities? At best, the project is but one of many factors, known and unknown, working in concert to affect the client population. Furthermore, meaningful results may only be observable over time. Succumbing to pressure to wrap things up quickly, project groups can be tempted to make definitive claims/statements too early on.

The preparation of this report entailed the following steps. All project materials supplied were examined in detail, including funding applications forms, work plans, project reports (activity, interim, annual, evaluation) and outputs. In the case of projects without reports, published project summaries (1999-2000, 2000-2001) were examined. On the basis of these materials, profiles of each individual project were prepared, by year and region, highlighting the critical information, relevant quotes, etc. Using these profiles, which had been reviewed and revised where necessary by regional project consultants, synthesis documents were then compiled, detailing (by funding/fiscal year, region and project) 1) *Project Partners*, 2) *Priority Populations*, 3) *Determinants of Health Addressed*, 4) *Outputs*, 5) *Outcomes* (intended and unintended), 6) *Client/Community Involvement*, 7) *What Worked*, 8) *What Did Not Work*, and 8) a broad category entitled *Learnings*.

In a further set of documents, all project outputs were sorted by year and type of output – e.g., *Gatherings* (consultation/planning, education/information, training, support groups); *Campaigns/media coverage* (education, fundraising, media [print/tv/radio]; *Resources* (print/audiovisual, collections, virtual/electronic, displays/booths/events, dramatic presentations); *Planning/strategy tools* (action plans/strategies, needs assessments, literature reviews, evaluations); and *Models/programs/approaches*. Regions and project sponsors were identified for each output, in brackets. The same process was followed with respect to project outcomes (changes achieved and/or planned), which were subdivided by target audience and type of outcome (e.g., knowledge, skills, health behaviours/attitudes, health and quality of life, social environments, mechanisms, systems/structures, etc).

The foregoing synthesis documents formed the basis for the detailed analysis, with successive drafts of the report being circulated to all relevant staff members (national and regional) for comments and feedback.

1 It should be noted that a standard reporting tool has been developed and will be implemented across all regions in fiscal year 2001-2002. Projects must report once per year using the tool.

2. The Hepatitis C Prevention, Support and Research Program

In September 1998, the federal Minister of Health announced a wide-ranging strategy to address hepatitis C. The basic aims are to improve blood safety, build knowledge about hepatitis C, and ensure that people infected with hepatitis C through the blood system do not incur out-of-pocket expenses for their medical treatment.

As part of the federal response to hepatitis C, the ***Hepatitis C Prevention, Support and Research Program*** was established in 1999 following wide stakeholder consultations. The Program has four major goals:

- to contribute to the *prevention* of hepatitis C infection;
- to *support* Canadians who are infected with, affected by, or at risk of developing hepatitis C, by encouraging the development and dissemination of useful tools and mechanisms;
- to foster *research* initiatives and increase research capacity – to both strengthen the evidence base guiding policy/program development, and expand the options for prevention, treatment and cure; and
- to strengthen the public's potential to respond effectively to hepatitis C, by raising *awareness* and building the required *capacity*.

At the community level, the Hepatitis C Prevention, Support and Research Program works primarily through two components – *Prevention*, and *Community-Based Support*. Together, these components receive almost half of the program's five-year budget, or $21 million out of a total of $50 million. (Three other program components – *Care and Treatment Support*, *Research*, and *Management, Policy, Evaluation and Public Involvement* – account for the remainder.)

The **Prevention** component seeks to:

- contribute to measures aimed at preventing the spread of the hepatitis C virus (HCV), especially among those at greatest risk;
- build the necessary commitment and capacity in key societal sectors and institutions to collaboratively pursue and support integrated prevention measures.

The **Community-Based Support** component focuses on awareness and capacity-building activities that strengthen local support. Specifically, its objectives are to:

- contribute to increased public understanding of the nature and effects of hepatitis C, thereby creating a more sensitive and supportive climate for persons infected with, affected by, or at risk of hepatitis C infection;
- increase the capacity of regional/local community-based organizations to support such persons.

3. Regional Project Funding

3.1 Objectives and Priorities

In October 1999, the *Hepatitis C Prevention, Support and Research Program* began making project funding available to local, regional and national organizations that were committed to addressing hepatitis C collaboratively at the community level. Regional project funding, administered by Health Canada through its offices located in six geographical "regions" across the country[2], seeks to:

- support a strong community-based response to the needs of persons infected with, affected by or at risk of hepatitis C;
- increase collaboration among community organizations; and
- secure a voice for such organizations in the national Hepatitis C Program.

In 1999-2000 – the first funding year – there was an emphasis on care and support initiatives directed to persons infected with/affected by hepatitis C, encompassing the following:

- *funding* and *capacity-building support* for organizations undertaking initiatives on behalf of persons infected/affected, or at risk of hepatitis C infection;
- *funding* support for the *development and evaluation of community-based programming* in response to the needs of such persons.

Up to ten percent of "year one" funding was available for prevention projects, in the expectation that community-level experience gained in the first year would help to inform prevention-related initiatives in subsequent years. Year two saw an infusion of more monies for prevention projects, coupled with a continuation of funding for care and support initiatives. As well, regions began community consultations with a view to identifying their most urgent needs and determining how best to address them. The resulting priorities drove each region's solicitation process.

3.2 Guiding Principles

Project applicants were encouraged to work from a community development perspective – i.e., to meaningfully involve the intended populations at every stage possible – and to follow the same principles that guide and inform the Hepatitis C Prevention, Support and Research Program. These principles underline the need to:

2 The term "region" as used in this report refers to one of the following: Atlantic Region (Newfoundland and Labrador, Prince Edward Island, Nova Scotia, New Brunswick); Quebec; Ontario/Nunavut; Manitoba/Saskatchewan; Alberta/Northwest Territories; British Columbia/Yukon. Program Consultants in each regional office are charged with administering, tracking and securing reports from all projects funded in their respective regions by the Hepatitis C Prevention, Support and Research Program.

- base decisions on the best evidence obtainable;
- use a population health approach (i.e., work from a "determinants of health perspective");
- meet the needs and priorities of people who have hepatitis C, those at risk of becoming infected, and others closely affected (such as family and caregivers);
- find practical, immediate ways of making people's lives better;
- contribute to initiatives that will last;
- treat everyone with hepatitis C equitably, regardless of how or when they contracted the virus;
- keep overhead costs down;
- work closely with community partners, other (i.e., non-health) sectors, and the institutions of society;
- make sure that community efforts are coordinated and complementary;
- track results and performance, in order to continue learning and improving.

3.3 Application Requirements

Against this background, applicant groups/agencies were invited to submit their proposed *work plans* (spelling out goals, objectives, specific activities and expected results), together with *evaluation plans* (how they plan to assess whether goals/objectives have been met, and pinpoint factors or conditions that may have helped or hindered the process). Applicants were also asked to identify all *project partners* and the *roles and responsibilities* expected of each. Where appropriate, *sustainability plans* were also requested (how the initiative might continue after the funding period).

4. Overview of Projects Funded

A total of 110 projects were funded during fiscal year 2000-2001 and were thus eligible to be included in this report[3]. These encompassed:

- projects funded in year one (1999-2000) and completed in year two (2000-2001);
- year one (1999-2000) projects that received additional funding in year two (2000-2001) – e.g., to undertake follow-up or new activities;
- projects funded in year two (2000-2001) and either completed or still in progress at year-end (March 31, 2001).

During 2000-2001, the Program disbursed a total of $3,113,000 for projects in all regions of the country. The initiatives funded were varied, and focussed on community and organizational aspects of responding to hepatitis C, preventing the spread of the disease through educational and other means, and addressing the needs of specific populations.

Ninety projects received funding for the first time in 2000-2001, and another 20 projects were carried forward from 1999-2000. In terms of size and time frame, these projects ranged from a five-month $7,000 initiative to a $153,000 endeavour spanning 36 months.

By the end of the fiscal year, 25 of the 90 *new* projects had been completed, 65 were still under way, and five had not yet commenced. Of the *grand total* of 110 projects funded in 2000-2001, 32 had been completed by March 31, 2001, and 78 were still under way.

The breakdown of projects by region is shown in Table 1 below.

Table 1:
Distribution of funded projects, by region (2000-2001)

Region	2000/01	(from 1999/00)	Total (Projects)
Atlantic	9	(0)	9
Quebec	11	(4)	15
Ontario/Nunavut	27	(8)	35
Manitoba/Saskatchewan	8	(2)	10
Alberta/NWT	15	(3)	18
BC/Yukon	20	(3)	23
Total	**90**	**(20)**	**110**

3 Subject to the receipt of their written reports by the deadline of February 15, 2002.

4.1 Project Issues and Themes

The second funding year saw a continuation of the literature reviews, needs assessments and other preliminary activities that had characterized year one, coupled with a focus on strengthening community/organizational skills and knowledge, and determining how to respond to identified needs. It was not uncommon for projects to undertake a mix of these activities.

There were four main clusters of activity:

i) *information collection* (to meet the need for more/improved information as a prerequisite to the development and targeting of meaningful initiatives);

ii) *capacity-building* (to meet the need for adequate skills and knowledge, appropriate systems, structures and strategies, and strong partnerships and linkages – the "basics" of effective interventions);

iii) *outreach/support* to persons infected/affected/at risk (to reach and meet people "where they are at", and to address their immediate, day-to-day needs);

iv) *awareness/education* (to meet people's need for information about hepatitis C, its risk factors, modes of transmission, symptoms, progression, treatment options and management – and about sources of assistance and support).

Information collection and *capacity-building* activities affect organizations and their personnel and *outreach/support* and *awareness raising/education* activities affect client populations (persons infected, affected, at risk).

a) Information Collection

The collection of baseline information remained a core activity in year two. Efforts to clarify and document local-level hepatitis C-related issues focussed on:

- identifying populations at risk or in need;
- determining the coping skills, support concerns and information requirements of such populations and their subgroups (each facing particular barriers);
- pinpointing gaps in the knowledge, skills, structures, programming and resources of a wide array of community service-providing organizations, their staff and volunteers.

Populations and their needs

Many projects attempted to document the needs of specific client populations, as well as the community groups/agencies and workers serving them. Such initiatives were aimed variously at:

i) *Infected and affected groups*, including those for whom a hepatitis C diagnosis can be especially complex and challenging (e.g., persons with hemophilia or HIV/AIDS);

ii) *Populations at risk*, reflecting a recognition that support measures – while important and necessary – need to be backed up with preventive measures (e.g., an examination of the risk behaviours and education needs of Calgary's rave community);

iii) *Community organizations/groups* (e.g., an environmental scan and assessment of the research needs of HIV/AIDS-related groups concerning their ability to address co-infection, prevention, service and support issues);

iv) *Service providers* (e.g., an assessment of the needs of medical practitioners serving hepatitis C-infected homeless persons).

A number of projects also sought to identify *hepatitis C-infected/affected/at risk* populations in defined areas (e.g., health regions and/or districts; areas served by local chapters of national non governmental organizations [NGOs]; urban and rural areas).

Approaches

Several projects began by conducting literature reviews, aimed either at documenting the facts about hepatitis C (risks, transmission, treatment and care) or probing topics related to intervention planning (e.g., adult learning styles, learning in a correctional facility).

Projects also gathered information directly from their client populations and the groups/personnel serving them through community forums and consultations, focus groups, face-to-face interviews, telephone surveys, and written questionnaires.

Uses of information

Projects identified a wide range of uses for the information collected:

- to *establish provincial priorities* on education, prevention and support services and programming for hepatitis C-infected persons and their families;
- to *inform the development of infra structural, educational and support programs* for hepatitis C-positive persons with hemophilia and their families across the life stages;
- to *improve the coordination of partnerships with community groups*;
- to *design an educational conference* to meet local service providers' identified needs;
- to *enhance staff skills* within community-based organizations, through training and resource development.

b) **Capacity-Building**

Information gathering supplies the evidence that is needed in order to do effective capacity-building. With reliable information, groups/agencies are better placed to identify strengths and weaknesses in community service systems and structures, and to clarify what action is needed to fill the gaps.

As the year two projects show, capacity-building can occur at different levels. For example, after assessing community needs groups/agencies may conclude that they need to upgrade their knowledge and/or skills, or they may decide to develop new models or redesign existing structures, or perhaps to concentrate on strengthening community linkages. Each type of activity is discussed below.

Worker education and training

Across all regions, projects placed considerable importance on improving staff/frontline skills and knowledge and developed activities for various groups:

- public health and hospital workers (including emergency department nurses);
- non-professional workers serving persons with addictions;
- volunteers working with street populations and youth;
- correctional/prison officers;
- non governmental organization staff and volunteers;
- pharmacists;
- community workers in potential contact with hepatitis C-infected persons, including police, firefighters and paramedics;
- general practitioners.

A number of projects targeted all or most of their resources to worker training, whereas others addressed both worker and client needs.

These worker training sessions took many forms, based on the type of information to be conveyed and the needs and learning styles of the groups involved. They included the following:

- conferences, panel discussions and round-table meetings;
- workshops, including "train-the-trainer"and peer-led sessions;
- continuing education and other seminars (e.g., for medical professionals);
- community forums, educational "speaks" (e.g., for workers in group homes);
- presentations and information sessions (for staff in men's shelters, drop-ins, Aboriginal-serving groups, addictions agencies, detention facilities and public health departments).

A wide range of material about hepatitis C and related subjects was presented to service providers:

- basic information on symptoms, disease progression, co-infection, and treatment options;
- methods and techniques – e.g., hepatitis C prevention/intervention, peer counselling, and support group facilitation;
- information on "bigger picture" issues, such as the determinants of health.

Model development and redesign

At least two projects sought to create new models for dealing with hepatitis C challenges. One of these was a proposed joint community/federal/territorial initiative by the Native Women's Association of the Northwest Territories (NWT). Its goal was to develop a new funding model for HIV and hepatitis C prevention/awareness projects in NWT communities. The other project, an outreach initiative, was already under way when the need became apparent for an in-house protocol on hepatitis C testing, counselling and follow-up. The project responded to this need by developing the necessary protocol.

A number of groups/agencies found that they lacked the tools and/or infrastructure needed to tackle hepatitis C effectively. They used their funding to make the needed changes – for example, to:

- integrate hepatitis C issues into the mandate, expertise and programs of a local community council charged with planning/programming in blood-borne pathogens and harm reduction outreach;
- incorporate Aboriginal/spiritual values and concepts into the delivery of education, prevention/harm reduction and support to inmates;
- adapt an information manual to the needs of smaller communities and volunteer-run programs.

Collaboration

Reflecting a growing recognition of the benefits of sharing – not only of resources, expertise and experience but also of visions and goals – many initiatives focused on "building bridges" within, between and beyond communities.

Collaboration was commonplace in the projects (a funding requirement). However, some groups explicitly aimed their activities at increasing the linkages among concerned community agencies/sectors. Many groups chose to formalize their connections with partners and other stakeholders from the start, by establishing work teams. Other groups reached out into the community for specific types of assistance – for example, to the media for publicity, to community centres and churches for meeting

space, to local clubs for resource dissemination, to schools for classroom time, and to businesses for sponsorship and the underwriting of products/events. Many projects built and strengthened networks by sponsoring conferences, linking up with groups and institutions outside the region, sharing resources with sister agencies/groups, and/or sitting on each other's committees.

The reports reveal that many beneficial connections were formed or reinforced as a result of all these activities. Reflecting on the advantages of collaboration, groups said that working with others had helped them to extend their reach, raise the profile of hepatitis C issues locally, increase their own visibility and credibility, and lay the foundation for future collaboration – all strong indicators of growing community capacity. Other encouraging signs of capacity development reported by groups and communities included the following:

- their increased ability to influence decision-making;
- increased membership/greater visibility of the group/agency;
- an expanded volunteer base;
- improved coordination, planning and referral systems;
- new partnerships with remote/rural communities;
- improved fund raising ability;
- a greater sense of confidence and effectiveness among volunteer/peer workers.

c) Outreach and Support

In year two, outreach and support remained central features of project activities. Many initiatives, especially in communities receiving funding for the first time, sought to increase the availability and accessibility of *support* – immediate practical assistance to those infected with/affected by hepatitis C. The assistance took many forms, and included facilitating access to medical treatment and specialist care, self-help, advocacy and other community programs and services ("walk-in" support, one-on-one counselling/follow-up, telephone help lines/referrals, etc.).

Many projects launched active *outreach* initiatives to client populations that, for social, cultural, language or other reasons, are often difficult to reach. Such groups included inner-city dwellers – many of them poor, young, inadequately housed/homeless, or addicted – as well as individuals in trouble with the law and ethno cultural populations. One rural project even appointed an "Outreach Ambassador" to develop connections with the local drug-using community.

Project reports noted various challenges. In some communities, for example, there were difficulties associated with confidentiality. One report commented on the reluctance of clients living in outlying areas to visit the local clinics. These individuals apparently felt more secure travelling to a larger nearby town for services, and clients from *that* town

preferred to obtain services in the province's capital in order to protect *their* confidentiality.

Many groups sought to make local services and resources more accessible and available. Project activities in this category included the following:

- developing a credit-card sized "Hep C Help Card" with contact information and toll-free numbers;
- linking client populations to practical community resources (including housing, medical treatment, addictions treatment, transportation, and emotional support) to inner-city residents with hepatitis C;
- presenting information on hepatitis C to workers in remote camps, and leaving posters in the washrooms;
- developing a booklet series on risk, diagnosis, treatment special needs and concerns for injection drug users, including access points for specialist care.

A critical aspect of outreach and support was ensuring that the activities were appropriate to the population in question – be they women in conflict with the law, Aboriginal persons, sex trade workers, inmates/parolees or injection drug users. In addition, projects recognized that clients can face many different challenges. To address communication barriers, one project developed a brochure on "How to talk to your doctor about hepatitis C" and – to help clients lead a relatively "normal" life – a another brochure entitled "You are not your disease, or are you?".

d) Awareness and Education

Information was developed and disseminated in various forms to infected/affected/at risk populations. Groups also sought to combat persistent myths and misconceptions about hepatitis C – for example, a notion reportedly held by street youth in one city that hepatitis C was no more dangerous than getting the flu.

Confidentiality emerged as a major concern for some awareness-raising projects. Their reports alluded to the existence of "hidden" populations in need of accurate information – for example, rural and other small-community dwellers too embarrassed to come to public events or to talk to local health professionals. One project report noted that in the context of "small town" culture, injecting drugs is a very secretive behaviour. It surmised that in the absence of any observable population of injection drug users, local people were less likely to be aware of the dangers.

Across the country, education and awareness-raising efforts sought to overcome these and other barriers, by making appropriate, understandable, practical information available and accessible to people in the forms and forums least likely to intimidate them. While a number of initiatives were aimed at "the public"– for example, through pamphlets, public service announcements and newspaper articles – most were carefully

targeted to specific audiences. Written/printed materials of all types were created, tested and distributed to sites frequented by particular groups:

- pharmacies, for individuals who used needles to inject prescription and non-prescription drugs;
- clubs, for the rave community;
- friendship centres, for Aboriginal people;
- drop-ins, shelters, and similar venues for street youth and adults;
- web sites, for some communities (e.g., persons with thalassemia).

Many of the resources were designed to address the support needs of people already infected/affected. In addition, risk and prevention were prominent themes. Examples included posters (e.g., "Are you at Risk?"), orientation packages for inmates upon entry and release from prison, a 90-page workbook with information on hepatitis C risk factors incorporating Aboriginal teachings, and "Prevent and Protect", a pamphlet directed to injection drug users.

Language was recognized as a barrier for some populations. A British Columbia project translated its resources into French, Spanish and a number of East Asian, South Asian and South East Asian languages. Projects in Ontario and Atlantic Canada targeted Francophone populations, and several bilingual resources were created, including newsletters and web sites. One Quebec initiative reached out to English-speaking, Italian, Vietnamese and other language groups. Other projects used graphic approaches, educational games and playing cards with a hepatitis C theme to overcome literacy barriers among street populations and prison inmates.

Among the diverse approaches used to educate clients and raise their awareness were:

- school health fairs and class presentations;
- workshops and impromptu sessions for street populations;
- a "family weekend" for hepatitis C-infected persons with hemophilia and their families;
- presentations to female prison inmates;
- information booths and shopping centre displays;
- a tattoo art contest and drama skits on high-risk behaviours for youth.

4.2 Project Approaches

Projects varied widely in both scope and complexity. In some instances their activities were designed to unfold sequentially – in effect, building one on the other. An example of this type of project is the (still ongoing) "Model Development and Implementation of Hepatitis C Services for the Homeless in Calgary". Sponsored by the Calgary Urban Project Society (CUPS) Community Health Centre, this project comprises three distinct phases:

- to identify barriers to hepatitis C testing, treatment and support for homeless people;
- to adapt existing methods of service to address these barriers;
- (using a model development approach) to identify key elements of a comprehensive strategy to effectively meet the needs of the client population.

Also common were projects comprising several independent activity sets that could either run concurrently or overlap in time. For example, the York Region Chapter of the Hepatitis C Society of Canada undertook to:

- raise the profile of its work with the local media;
- support public forums on hepatitis C;
- conduct monthly support group meetings; and
- create a directory of community services.

Still other projects were single-focused – for example, a training initiative entitled "Hépatite C sans frontières". In a series of one-day workshops, this Quebec project trained non-professional community health and social service providers such as community addiction workers, street workers and youth centre workers, to engage in preventive and other interventions with their respective clienteles.

4.3 Groups and Organizations

As in year one, nationally-focused NGO's played a part in most projects. Approximately one-third of all the year two initiatives were sponsored by these NGOs (or their chapters); they were directly concerned with:

- hepatitis C specifically (e.g., Hepatitis C Society of Canada) or liver disease in general (e.g., Canadian Liver Foundation);
- related *health* issues (e.g., Canadian Hemophilia Society, Thalassemia Foundation of Canada, Canadian Mental Health Association);
- related *social* issues (e.g., the Elizabeth Fry and John Howard Societies).

Year two saw an encouraging upswing in the number of projects undertaken by groups that were themselves partnerships – for example, coalitions, committees or networks encompassing several community agencies/groups. This suggests that the benefits of working together are already apparent in many communities. The "partnership groups" included many that were HIV/AIDS-related. Non-HIV/AIDS examples included a harm reduction committee (Chatham-Kent), a street-health coalition, and an interprovincial initiative involving groups from New Brunswick and Prince Edward Island (Atlantic Region).

Besides national NGOs and coalitions, funding recipients included an array of local, regional and community-based groups/agencies:

- public health units and health districts/boards[4];
- community health and Aboriginal health/friendship centres;
- street-health groups;
- resource centres and support groups;
- youth organizations;
- addictions agencies.

4.4 Partners

In their reports, project groups were inconsistent in their interpretation of the word "partner"[5]. Some groups identified their major partners only, whereas others listed virtually every organization they had worked with during the course of their project – more than 20 in some cases. (An example of this was "A Living Support Project Using a Holistic Healing Approach", organized by the John Howard Society of Manitoba, which involved between 25 and 30 different groups). At the other extreme were project reports that referred to their partners generically (as "stakeholders", "community organizations"or "hospitals"), rather than naming them directly.

Somewhat surprisingly, approximately 20 percent of the projects made no mention of partners at all. Of these, a small number were groups receiving small one-time community grants for "support group development and capacity-building" activities, which may have been undertaken singlehandedly (few reports received). Other such projects were undertaken by chapters of national NGOs, and frequently involved in-house capacity building activities. As a group, NGO-run projects appeared to involve fewer partners than those undertaken by other types of groups/agencies. However, there were some exceptions to this.

4 Public health units and health district authorities/boards sponsored various projects undertaken by fledgling hepatitis C groups/organizations, working in partnership with them.

5 The Program's funding application form defines "partner" as "a person or organization who makes a contribution to the project (funds, time, expertise, services, space, publicity, equipment, materials, etc)."

Most projects drew in at least three partners. Reflecting the breadth of community interest and concern and the Program's *Guiding Principle* on working closely with community partners, other (i.e., non-health) sectors and society's institutions these partners came from:

- community health and social service agencies – e.g., public health units, community health centres, needle exchanges, substance abuse agencies;
- client groups – e.g., Safer Crack Coalition, Illicit Drug Users Union of Toronto; inmates committees;
- educational organizations – e.g., universities/colleges, school boards and districts;
- law enforcement and corrections-related bodies – e.g., police, RCMP, justice departments, correctional facilities;
- community/advocacy groups and agencies – e.g., United Way, food banks, citizens' and women's action groups;
- health/medical professionals and their associations – e.g., pharmacists;
- businesses – e.g., pharmaceutical companies, tattoo shops;
- ethno cultural organizations;
- media outlets, both community and national.

Upon receiving their funding, approximately one-sixth of the projects formed committees, working groups, panels or similar bodies. In some cases, these groups steered the project, in others their role was advisory, and in still others they assisted with evaluations. Their membership was drawn variously from partner groups/agencies, peer groups and other community sources.

As discussed under *Capacity-building*, some projects directly named the strengthening of a network/partnership as one of their objectives. Other projects seemed to take for granted that working collaboratively would have this effect. An analysis of project results suggests that, in general, these expectations were borne out.

4.5 Populations

Client groups

Over one-third of the projects from across all regions identified their "priority populations" generically as:

- hepatitis C-infected groups;
- groups affected by hepatitis C (spouses, families, caregivers, social support networks);
- groups at risk of contracting hepatitis C.

While approximately 15 projects aimed their activities at the "general public", it was more common for clients to be defined according to their demographic characteristics or social circumstances, such as:

- geographic location – e.g., residents of Quebec's Mauricie Region, Alberta's Grande Prairie area;
- *setting* – e.g., rural (or "non-urban"), urban (or "inner-city") dwellers;
- *social circumstances* – e.g., street-involved, homeless, marginalized persons;
- *legal circumstances/status* – e.g., individuals entering, serving in or leaving correctional institutions (variously described as federal or provincial inmates, parolees, and women in conflict with the law);
- *risk circumstances/behaviours* – e.g., injection drug-users (prescription and/or non-prescription), sex trade workers;
- *health status* – e.g., co-infection (persons infected with both HIV and hepatitis C virus; persons with hemophilia infected with hepatitis C virus and/or HIV; and persons infected with hepatitis B and C and/or HIV);
- *age* – e.g., youth;
- *gender*;
- *ethno cultural origin and/or language* – e.g., Aboriginal populations, Vietnamese and Italian-speaking residents of Montreal.

Reflecting the complexity of the issues, many projects directed their activities to a clientele that combined several of these characteristics – for example, the youth population (including individuals who were street-involved, addicted/injection drug users and/or incarcerated).

Health and community workers

Approximately half of the projects funded in 2000-2001 targeted frontline and other staff, professional and non-professional health/social service providers and/or volunteers and peer helpers.

4.6 Determinants of Health

Among the major factors known to influence the health of populations are gender, culture, income/social status, education, employment and working conditions, the physical and social environments, personal health practices/coping skills, the availability of social support networks, and health services. Known as the determinants of health, these factors may act individually or in combination. To encourage project organizers to take a broader perspective when developing and delivering their interventions, the funding application requires that they specify the health determinants they plan to address.

Disappointingly, many projects made no reference at all to the determinants of health in their reports. This lends credence to the remark of one regional program consultant that "the determinants of health are never talked about after the application form is filled in."[6] Even so, it does appear from the reports that an appreciable number of groups – especially those operating at the front lines (streets, prisons, etc) – have an instinctive grasp of the connections between health risk and various forms of disadvantage. Judging from their project approaches, attention to social barriers, sensitivity to client realities, and their descriptions of desired outcomes, these groups have a solid understanding of what, ultimately, determines health.

Most projects addressed more than one determinant of health. As Table 2 shows, the health determinant most frequently addressed by the year two initiatives was *personal health practices and coping skills* (72 projects), followed by *social support networks* (69 projects). To some degree this reflects the priority accorded to support initiatives – those concerned with providing immediate practical measures that will make a difference in people's lives. A large number of projects (45) also addressed *culture* – i.e., barriers and/or issues facing populations with distinctive languages, beliefs, values and understandings (such as Aboriginal peoples, ethno cultural groups, and the youth, drug, street and prison subcultures).

Table 2:
Determinants of health addressed or identified by projects (2000-2001)

Health Determinant	Projects[1] (addressing/identifying)
Gender	2
Culture[2]	45
Income/social status	6
Education[3]	18
Employment/working conditions	1
Physical/social environments	26
Personal health practices/coping skills[4]	72
Availability of social support networks	69
Health services	24

1 Most projects addressed multiple determinants.

2 Broadly interpreted to include barriers/issues facing not only Aboriginal peoples and ethno cultural populations, but also the youth, drug, street and prison cultures, each with its own language, beliefs, values, etc.

3 See discussion below.

4 Some projects addressed both, while some addressed only one.

6 In such cases, the project reports and other materials were reviewed to establish "implied determinants", which were then verified with regional project consultants.

Some misunderstanding appeared to surround the meaning of *education* as a determinant of health. Although 18 projects identified education as one of their determinants, with several possible exceptions (such as the use of low-literacy materials and graphic/non-written approaches), their educational interventions were of a "downstream" rather than an "upstream" nature. In other words, they were seeking behaviour changes, not tackling root educational deficits – something that initiatives of this type would be virtually powerless to do.

Although addressing certain aspects of the determinants of health was beyond the scope of their projects, groups adopted a realistic approach to the challenge before them. Following are some of the ways in which projects addressed specific determinants:

- *personal health practices and coping skills*, largely through educational interventions;
- *social support networks*, through the formation of support groups (with opportunities for members to discuss issues among themselves), and through outreach to families and friends;
- *social environments*, through sensitivity training to service providers (to reduce social stigma) and community development work (to increase support for those infected);
- *culture*, through consultation with Elders and by incorporating the Medicine Wheel into Aboriginal education materials, using street-sensitive approaches with homeless populations and gender-sensitive interventions with women;
- *income* barriers, by helping clients to access child welfare, rent subsidies and social services, as well as government compensation and funding for medical expenses and health services.

An example of stakeholders understanding the determinants of health was provided by the Manitoba project, "Lights On". Its report noted: "The workshops ... made staff (who are predominantly Aboriginal) aware of statistical evidence showing the much higher prevalence of all types of hepatitis disease in their community. It was sobering to see the children and youth who come to [the facility] reflected in all the main risk factors associated with contracting all the hepatitis type diseases". The report noted that "the strongest determinant of health appears to be income level – poverty", and pointed to the importance of linking not just hepatitis C but also other health issues – AIDS, drugs and alcohol, sexual behaviours – with the determinants of health. It concluded: "Through analysis of the determinants of health there is a greater recognition among funders and other service providers of the impact we [the sponsoring organization] have on at risk youth's health."

Hepatitis C virus tends to thrive in conditions of social inequality. Living on the margins of society – be it on the street, crowded into a shelter, in prison, or unemployed on a remote reserve – increases the risk of transmission. Recognizing this, at least two projects set time and resources aside to inform key project participants about the determinants of health and their links to hepatitis C. In one instance, a regional health authority organized a workshop

for stakeholders on the social determinants of health. In another, an AIDS-related group discussed the determinants of health with its peer educators as part of their training.

Ultimately, changes related to the determinants of health – sometimes requiring decisions beyond the health sector – are what will really make a difference. Understanding this, community-serving groups working at the front lines (including larger, national-level NGOs) often complement their community initiatives with advocacy efforts, which they see as an important part of their role.

4.7 Involvement of Client Populations

Capacity-building is not just about organizations. It is about community people, whose support and involvement at every stage are vital to the success, continued growth and sustainability of local initiatives. Many projects recognized the potential benefits of involving hepatitis C-infected or affected persons in their activities – not just as an add-on, for political correctness, but because it was effective.

The majority of groups involved clients actively in at least one phase of their project. In some instances, clients participated with other stakeholders on formal advisory committees and work teams. As well, clients frequently contributed to needs assessments through focus groups, community meetings, questionnaires and informal encounters.

Several projects involved client group members in virtually all of their activities. One such project, "Hepatitis C Education in a Correctional Setting", detailed the ways in which hepatitis C-infected/affected inmates, including injection drug users, had participated in project activities. As members of the advisory committee and project working group, clients had provided direction on needs and possible educational approaches, and played a key role in the development of educational tools. Plans called for their continued involvement, by giving advice and feedback, and in the pilot testing of resources. Another project envisaged client participation at every major stage, from needs identification through program planning, delivery (as trained peer educators), and evaluation.

Between 10 and 15 percent of the project groups said that they had called on client expertise in the planning, development and/or delivery of their interventions. Among other things, clients reportedly helped to:

- plan conferences and panel discussions;
- design and create tools and resources – e.g., a newsletter carrying client "personal accounts and stories", and a prevention kit for prison populations;
- develop and perform in educational drama skits/plays (for schools, young audiences).

Perhaps the widest use of client groups was in the review (focus testing) of resources. More than one in 10 projects reported seeking out clients for feedback and pilot testing. In a single region alone, HIV/HCV co-infected prisoners, young offenders, marginalized inner-city populations and Aboriginal persons were involved in activities of this kind.

Projects found various other ways to capitalize on their clients' special knowledge and expertise. For example, clients were recruited to:

- help access priority populations (e.g., fellow inmates when detention centre staff members refused to cooperate);
- offer specialized guidance (e.g., on safe injecting practices);
- facilitate or co-facilitate support groups;
- help gather and deliver information (in one correctional institution's prevention/education program, inmates and Elders played a "crucial" role as information channels).

5. Project Results

5.1 Definitions

Outputs are defined in the project funding application form as "the products and events that will *result* from the project." They may include:

- *one-time or time-limited events*, such as
  - meetings (for consultation, educational, planning and/or training purposes);
  - training sessions;
  - campaigns (public education, fundraising);
  - displays; and
- *products*, such as
  - resources (manuals, pamphlets, newsletters, directories, videos);
  - reports;
  - planning/strategy tools (action plans/strategies, needs assessments, literature reviews, surveys, evaluations);
  - models/approaches (e.g., peer education programs).

Outcomes are defined in the funding application form as "the changes/improvements expected to occur as a result of the project." They may include:

- *changes* – for example:
  - in health status, knowledge/awareness, attitudes, behaviours;
  - at the level of the determinants of health – e.g., in the social, physical or service environments;
- *mechanisms* (e.g., a steering committee, a strategy).

In 2000-2001, these concepts were still relatively new to some community groups, and a certain amount of confusion still surrounded their interpretation. (For example, a support group resulting from project activities was classified in some reports as an output and in others as an outcome.) However, in an effort to enhance the quality and value of project evaluation activities, a standard reporting tool will be introduced across all regions in fiscal year 2001-2002. This tool will help to ensure that groups have a common understanding of key evaluation reporting terms.

5.2 Project Outputs

The volume of outputs rose appreciably in 2000-2001, compared with 1999-2000. This was due to stepped-up activity in the Program as it moved into the second year of funding. A wide assortment of outputs were recorded.

Consultation and planning sessions showed a marked increase in year two, as more groups began meeting and mobilizing their communities, carrying out formal and informal studies of hepatitis C populations and their needs and concerns, and planning how to address these through long-term strategies, action plans, etc.

Information, education and training-related outputs also rose in year two, boosted by a host of capacity-building projects. For example, training and educational sessions (e.g., for stakeholders, staff and volunteers) showed a six-fold increase, and educational events for client populations rose by a factor of 16. The latter included:

- theatre training for at risk youth;
- community workshops for street populations on nutrition, safer sex and other practical issues;
- suppers and bingo sessions, providing an occasion for hepatitis C-related presentations;
- one-on-one counselling sessions with staff for homeless persons.

Support groups and their development were a main focus of activity, with almost half of the projects initiating or strengthening such groups. Many projects used the support group setting as an opportunity to inform/educate participants on issues ranging from compensation claims to nutrition.

The number of media *campaigns* did not register a similar increase. This is not surprising. Information from needs assessments has provided project organizers with a clearer picture of their audiences' needs and concerns, and a better idea of the tools and resources required to gain the attention and confidence of groups once considered "hard to reach" (e.g., because of low literacy).

Even so, a number of projects recognized the value of using the media to catch the audience's attention. This resulted in an assortment of press articles, press releases/advertisements, radio and television interviews, and a media roundtable on cable television (taped for future use).

The volume of *resources* produced in year two increased sharply (from 19 in year one to more than 130). An analysis of these resources – encompassing print/audio-visual materials, web sites, displays/booths in shopping malls, and dramatic presentations – reveals that many were carefully geared to particular audiences. In the print category, by far the largest resources included the following:

- a "Hepatitis C Handbook for Injectors";
- a pamphlet on safe tattooing and body-piercing for residents of a detoxification centre;
- various games (e.g., for youth);
- street language materials for homeless persons;
- listings of services for hepatitis C-infected/affected persons, injection drug users, and street populations.

Various electronic resources were also developed, including:

- hepatitis C web sites (including a bilingual one with links to Charity Village, HepCBC, HepCure and Hepatitis International);
- moderated e-mail discussion groups;
- a regular hepatitis C network "Updater" providing members of one national NGO with e-mailed information on living with liver disease, local programs, services and activities.

An assortment of *models, approaches and programs* were developed (or were in development) for specific purposes during the period under review:

- *education* programs, such as "Living with Hepatitis C", "Living with Liver Disease" (modified version), and a model educational strategy based on adult learning principles for use in prisons;
- peer-based *training* programs (e.g., for the rave community, inmates, young Aboriginal residents of treatment facilities, and volunteers providing support to affected groups);
- a medicine wheel *teaching* model;
- *harm reduction* programs.

Some groups took on the challenge of creating comprehensive models to meet the awareness, education and support needs of particular populations (homeless persons, inner-city dwellers).

Less easy to define, but of clear significance, was a sprinkling of actual and planned outputs that are perhaps best described as capacity-building tools. These outputs included the following:

- three databases developed by organizations for their own use (identifying relevant contacts/resources and other links, potential funders, and a mailing list for e-mail/internet information);
- a conference report;
- a software tool to facilitate data analysis;
- a policy and procedures manual;
- volunteer guidelines and recruitment tools (applications, position descriptions, volunteer agreements);
- a fund raising manual.

5.3 Project Outcomes

a) Intended Outcomes

Intended outcomes are those changes that occur as planned or anticipated over the short, intermediate or long term. They are the positive changes of a continuing nature that are intentionally sought by groups initiating projects. Most projects funded under the Program are aimed at bringing about short- and intermediate-term changes. On their own, such changes can seem small and insignificant. However, taken together over time they can assume great weight and eventually, through their combined effect, lead to the accomplishment of longer-term community health goals.

A review of outcomes sought and/or achieved in year two reveals three main groupings:

- those that are ***ameliorative***, operating to relieve the distress, isolation and lack of support experienced by infected/affected populations;
- those that are ***preventative/harm-reducing***, helping to halt or reduce spread of hepatitis C to populations at risk;
- those that are ***instrumental*** in the sense that they provide the *means* by which much of the desired change can be effected, especially over the long term.

i) Ameliorative outcomes[7]

A large number of initiatives sought to lessen the impact of an hepatitis C diagnosis on individuals, their families and friends through education, skills-building and support, by increasing their sense of control over their own health (empowerment) and improving their health practices. A number of projects also sought to effect positive changes in the social environment to make it more supportive of those affected by hepatitis C.

Knowledge and skills

Intended outcomes in this grouping included a better understanding on the part of the client populations about many aspects of the disease. For example, *knowledge* gains were reported relating to:

- hepatitis C itself, and the access points for community services;
- treatment options and research into hepatitis C and hemophilia for members of a hemophilia organization;
- the disease process and healthy behaviours, for hepatitis C patients and their families.

Skills-related outcomes identified in the project reports included:

- improved coping skills in hepatitis C-positive individuals with bleeding disorders and their families;
- improved ability to communicate with physicians;
- improved self-care skills for hepatitis C-positive persons.

Support

Client outcomes related to support included:

- increased ability to participate in a support group;
- enhanced links among several infected/affected inner-city clients who might form the core of a future support group (i.e., in stage 2 of project);
- increased sharing and mutual support among those infected and their "immediate circle";
- an increased sense of community (i.e., decreased social isolation) among infected or co-infected street-involved youth.

7 Implying changes in the populations infected/affected, and in the social environment.

Social environment

A supportive social environment is crucially important for those whose lives are affected by hepatitis C. Perhaps because of its frequent association with injection drug use, hepatitis C appears to stir prejudice and fear in people, and hepatitis C-positive individuals – especially those living in small communities – can be too embarrassed or ashamed to seek help. Accordingly, some projects developed initiatives to change the social environment. Their aim was to increase the sensitivity of community groups/agencies and their personnel to the often overwhelming social barriers faced by persons already disadvantaged because of their illness. With more sensitive staff and approaches, clients can at least find a "safe zone". Among the positive effects reportedly observed were:

- improved agency attitudes to street-involved youth in a large city;
- a more supportive environment, including more sensitive, non-judgmental, compassionate attitudes towards inner-city populations struggling with homelessness, poverty and substance use;
- the provision of "accessible care and treatment without stigma or discrimination"; and
- increased understanding and sensitivity within community health and service groups/agencies concerning the reality of being infected with hepatitis C, and living as an injection drug user.

Empowerment

Yet another set of outcomes was noted in the reports. These outcomes appear to reflect the net gains derived from any or all of the above, in empowerment terms – i.e., the positive overall effect that is experienced by people whose knowledge and skills have increased, and who feel more accepted and supported. Groups for whom such outcomes were reported included:

- hepatitis C-positive individuals living in the urban core, who reported an increased ability to assess their own situation and cope, act and plan for the future;
- residents of a large rural/small town district, who reportedly experienced an improved quality of life and lifestyle gains with respect to nutrition, hygiene, medical compliance, and drug and alcohol consumption;
- hepatitis C-infected/affected residents of a remote rural region, whose stress and anxiety levels appeared to decrease;
- members of a hepatitis C "Healing Circle", who reported some improvements in their health practices.

ii) Prevention and harm reduction outcomes[8]

The outcomes in this category followed a similar overall pattern to those falling under the rubric of Support, in that they ranged from reports of enhanced knowledge and skills, through an increased sense of effectiveness and self-confidence, to improved health attitudes/practices. Positive environmental outcomes related to prevention and harm reduction were also reported.

Knowledge and skills

This group of reported outcomes included the following:

- increased awareness of hepatitis C and prevention strategies among hepatitis C-infected/co-infected inmates (federal and provincial);
- increased knowledge of injection drug risks and harm reduction techniques among injection drug users and homeless, under-housed and marginalized people living in the downtown area of a large city;
- increased knowledge of hepatitis C transmission (risk factors, consequences, etc) among non professional tattoo artists/body piercers who engage in potentially risky practices.

Sense of effectiveness

Outcomes illustrating a greater sense of effectiveness were the raised self-esteem and self-concept reported among inner-city youth who took part in an educational hepatitis C theatre project. These gains reportedly resulted from the new skills and knowledge they had acquired in the course of the experience.

Health practices

Following are some examples of improved client health practices, as reported by project groups:

- adoption of safer practices (i.e., use of clean injecting equipment and reduced needle-sharing) by an injection drug-using population;
- the safe disposal of used needles;
- higher rates of hepatitis C testing and by implication detection rates for at risk, street-involved youth in a mid-sized city; and
- positive behaviour changes" observed in male and female inmates of correctional institutions.

8 Implying changes in the population at risk, and in the social environment.

iii) Instrumental outcomes[9]

As discussed under Capacity-building (section 4.1.ii) many interventions sought to develop more effective mechanisms, systems, structures and skills to combat hepatitis C. The short- and medium-term outcomes of such initiatives are not ends in themselves, but instruments for achieving long-term population health outcomes. The following examples were noted.

Mechanisms

Intended outcomes in this category included the development of new community partnerships and the strengthening of existing ones. "Partnership" in this context is loosely construed to include collaborative groupings of all kinds, including project advisory committees, working groups and teams formed to conduct project-related activities, as well as broader (local and regional) service-provider networks and intersectoral partnerships.

As various projects demonstrated, collaborative mechanisms such as these provided a means whereby members could contribute their varied knowledge, skill sets and perspectives, as well as their expertise with specific populations (e.g., improving audience reach, ensuring informed input, and increasing the effectiveness of dissemination efforts). One Alberta project report noted that its workers had increased their knowledge in two new areas (methadone maintenance and the provincial process for organ transplantation) as a result of expanded collaboration. In Atlantic Canada, the close working relationship that evolved between project organizers and a needle exchange dramatically increased the project's ability to reach injection drug users.

The inclusion of clients in collaborative bodies provided an ongoing means of tapping into their worlds (for insights, project approaches, feedback on resources) as well as a chance to overcome stereotypes and prejudices on all sides. For example, a project in Saskatchewan reported that youth formerly in trouble with the law in Prince Albert had "forged a new relationship with adults [including law enforcement officials], based on respect and power-sharing, which now informs the project's direction". Their collaboration with the police had resulted in invitations to make 20 additional school presentations ("Who ever thought the police would listen to us?").

Increased coordination (as a result of committee work) also helped to reduce duplication of effort. One project group collaborating with a local health authority in Alberta was pleasantly surprised to find that the latter could supply needed data (on hepatitis C incidence in the region). This saved the group both time and effort. Another project commented, "Participating in the activities of other non-profit groups and organizations enabled us to learn their mandates and work together for

9 Implying changes in community and other organizations and their staff and volunteers.

the benefit of citizens without duplicating services ....we each enhance the other's work". With one notable exception (in which tensions arose between groups concerning the modes whereby their respective clienteles had become infected) working together also helped to ensure that the partners were in agreement on key issues, reducing the potential for community members to receive mixed or confusing messages. One report offered a blunt but succinct assessment of collaborative work: "Though cumbersome, the partnerships were effective."

When sectors and service providers work together, bolder initiatives become possible. Illustrating this were two initiatives, both involving a wide spectrum of agencies and organizations, that attempted to develop "comprehensive" and "whole-person" approaches. The breadth of knowledge and expertise at the table enabled these groups to cluster the issues rather than tackling them piecemeal.

Increased knowledge and awareness

Knowledge gains reportedly came in several areas: for example, various groups increased their basic understanding of hepatitis C, client needs, harm reduction principles, and ways to locate resources and assistance. Likewise, they and their workers acquired *skills* in outreach, communication, adult education, prevention and harm reduction, among others.

Changes in structures and systems

The reports identified a range of positive outcomes in this category, including:

- improved co-ordination, planning and referral systems;
- better overall accountability to clients;
- improved staff organization and arrangement of physical space; and
- streamlining of services.

By tailoring their interventions to community needs, many groups were able to facilitate client access to improvements in:

- *services* (more locations, easier accessibility, more convenient times);
- educational *events* (weekend dates, no charge for attendance);
- *information* (more understandable, more relevant, appropriate language, available confidentially, etc);
- *delivery modes* (peer education, community-based events, often including food, held in locations frequented by the client populations);
- *formats* (games, mobile displays, bingo sessions, suppers, and film discussions).

b) **Unintended Outcomes**

What happens unexpectedly often carries within it a seed of learning – a hint, possibly, that a different approach may be needed, a different resource tried, or another population included.

There were project groups that found they had miscalculated with respect to intended outcomes. While several groups were more successful than expected, this sometimes placed unforeseen demands on their resources. Initiatives of this kind included:

- a BC/Yukon project that reported higher than expected demand for its newsletters, as well as telephone-call and referral volumes;
- an Ontario project that was able to cancel plans for a telephone survey as a result of the high turnout at its public forum;
- a Saskatchewan group that reported receiving an unexpectedly high volume of requests for information and training from the public and, to its reported surprise, from medical professionals as well.

Other projects either overestimated or underestimated the level of effort or resources needed, or misjudged where the demand would come from. For example,

- in one project, organizers found that their involvement with a support group stretched out for longer than planned – the clients needed more time to become comfortable participating in a "group support system";
- projects in two regions reported that they unexpectedly had to dedicate resources to assisting clients with compensation claims (related to infection through the blood supply);
- another project received unexpected requests for collaboration with community agencies (e.g., the Salvation Army, and the province's alcohol and drug abuse commission) to support injection drug users.

Some projects identified "down sides" to increased networking and professional development. In one case, it was the continual need to "keep up" with leading-edge information and disseminate this to client populations. A similar concern was echoed by a group that found itself under pressure to revise information for staff, trainers and partners.

As one project report noted, "more partners means more visions are involved". This was an initiative in which stakeholders had constantly pressed for the content to be expanded to include their particular areas of expertise – abuse, street life, gender inequalities and cultural issues. In another project, a consortium met some resistance to a plan to expand its mandate that would include hepatitis C issues – one consortium member feared that a diluted mandate would reduce the organization's ability to focus on HIV issues.

On the whole, however, the unexpected results yielded by involvement with networks were considered beneficial. Two regional networks in Ontario collaborated on a previously unscheduled "mini hepatitis C conference", and a Manitoba project was pleasantly surprised by the number of individuals and groups across the country involved in hepatitis C issues at different levels, and by the willingness of the hepatitis community to share information. An inner-city project received offers of help from unexpected quarters (e.g., individuals and groups *not* infected, at risk or directly affected by hepatitis C who showed an interest in volunteering).

Unpredictability in their client populations stymied some projects. One Ontario group said it had experienced unexpected difficulty in attracting and retaining hepatitis C-positive individuals for its advisory committee. In Alberta, project workers reported that although clients had initially shown great interest in being trained as peer workers, and provided good input, they had failed to turn up at subsequent sessions. In contrast, the enthusiasm of their client populations caught some project workers off guard (for example, the receipt of unsolicited written input from an inmate in Atlantic Canada who had participated in an initial work group meeting, and the unexpectedly strong referral role played by peer workers in an Ontario initiative.)

6. Lessons Learned

Approximately two-thirds of the projects receiving funding in fiscal year 2000-2001 provided written reports on their activities and/or achievements. Some of these also supplied samples of their outputs. Nevertheless, the overall quality of project reporting was uneven in terms of clarity, completeness, level of detail, and care in preparation. For example, some reports were handwritten whereas others had been prepared with professional assistance (e.g., external evaluators). As well, some project reports reflected much more extensively on the projects' experience than others.

The following analysis cannot be said to reflect project experience as a whole, because of the variability in reporting, the absence of reports from a sizeable number of projects, and the fact that many initiatives were still in progress at year-end. Regrettably, these factors mean that some project accomplishments will be unsung and valuable learning experiences lost.

Many important issues, such as capacity-building, the determinants of health and the benefits of partnership have been examined in some detail in the preceding sections of this report. Studied with care these will yield a myriad of useful tips for future projects and pitfalls to avoid. This section takes a different approach. It is an attempt to discern, based on the reports received, what larger lessons communities may learn from year two, and how these lessons may be used to improve the focus and results of regional project funding.

Discussed under four main headings, the following lessons are all rooted in project experiences as reported from the field in 2000-2001:

- **Territoriality** is concerned with the need for priority populations to remain the paramount concern, and for organizations not to become deflected from their purpose by turf-related concerns.
- **Peer involvement** highlights the advantages and potential limitations of working with peers in community-based prevention, education and support initiatives.
- **Attention to detail** reflects on the importance of attending to seemingly small administrative and other details that could undermine project results, or even compromise the initiative.
- **A whole-person approach** discusses the need to maintain an integrated perspective when working with priority populations and shows how interventions that ignore people's wider circumstances can sometimes go awry.

a) Territoriality

> *Lesson:*
>
> **Community groups mirror the wider society, with all its prejudices and power struggles. In our efforts to combat hepatitis C, we must strive to find common ground rather than focusing on our differences.**

One of the Program's guiding principles is that everyone with hepatitis C should be treated equitably, regardless of how or when they contracted the virus.

The roll-up report for 1999-2000 referred to an emergent concern that the stigma perceived to be associated with HIV/AIDS might spill over to persons infected with hepatitis C. The report suggested that this fear needed to be addressed. Once again in 2000-2001 the same issue came to the fore. Two main areas of concern were highlighted.

The first was the reluctance of some hepatitis C-positive individuals to participate in groups including persons with HIV/AIDS. In the words of one project report, "some people would rather see HIV and HCV separated as soon as possible". From a practical standpoint, this attitude may prevent clients from having their hepatitis C-related needs met.

Second, some projects hinted at the existence of a "hierarchy" of distinction among hepatitis C-positive persons, based on the source of their infection (e.g., blood supply versus needle-sharing or other practices). One project report alluded to a "perceived persistent bias towards those who 'got' hepatitis C from injection drug use rather than through the blood supply", a bias that this report noted, "may influence the allocation of resources, and the establishment and implementation of priorities by individual organizations."

The perception of stigma did keep people from attending support group meetings in one project (which reported on the "unwillingness of persons other than those infected by the blood supply to come forward and reveal themselves by attending..."). Another event failed

to attract persons infected through recreational drug use, possibly because "the domination of those attributing infection to the blood system ... inhibited others from attending".

As a result of these strains, rifts appear to be opening up between community groups whose common goal is to reduce the toll of hepatitis C. For example, one group reported that the "greatest barrier to implementing activities was the lack of willingness to coordinate efforts coming from another area organization funded to do hepatitis C work." That organization had expressed the "wish that the association of hepatitis C with HIV and IDU not be publicly alluded to". By acceding, the project group felt that it had reduced its ability to reach the broader community with hepatitis C messages, advertise its services, and respond to advocacy issues. At the same time, the challenging organization offered no services in the community and did not take part in the work of the community planning consortium. Some members of the local hepatitis C population were thus left virtually without support. The project report concluded that while a certain amount of compromise is appropriate in order to minimize conflict, "we have learned that our focus must be on ensuring the service is provided, not on who does it".

This problem is not insurmountable. Projects commonly face the challenge of appealing to different subgroups in the hepatitis C population. Furthermore, the attitude of "righteousness that attends those infected by the blood system"is not a new phenomenon, at least to the AIDS community. Still, its persistence does raise key questions. One project report wondered whether persons infected with hepatitis C alone would indeed be less inclined to seek out services from an "HIV-specific" group. According to this report, the following questions need to be answered: Are the two (modes of infection; i.e. blood vs injection drug users, or types of infection; i.e. HIV or hepatitis C virus) compatible within one support organization? And (if so), will people come forward in smaller communities and rural areas? The group concerned plans to canvass community views on these questions.

b) Peer Involvement

Lesson:

While working with peers has the potential to benefit all concerned, it won't "just happen". We need to find the formula for successful peer involvement, bearing in mind that the necessary ingredients may vary from community to community.

For community projects, viewing members of the client population as equal allies can be a fruitful strategy. Clients are the ones whose health is at stake, and their expertise is important to community service providers. Not only do they hold the keys to reaching people, understanding their cultures and ways, and building their trust, but as well they can share the workload and monitor project impacts on the front lines.

Throughout their reports, community groups noted the many benefits accruing from peer involvement, including:

- increased audience reach;
- greater trust in and credibility for the organizing group;
- a more reliable and accurate understanding of client realities and needs;
- the possibility of developing more authentic interventions;
- an ongoing ability to monitor the "pulse" of the client population;
- a greater comfort level among clients themselves; and
- better-quality feedback.

An entirely peer-driven youth initiative in Alberta found a more tangible reason to celebrate the use of a peer approach – "recruiting youth who were enthusiastic about this project resulted in lower spending on staff hours..."

When peers become involved they themselves also benefit. This is illustrated by a Vancouver initiative still under way at year-end. In order to reach youth outside the public school system (e.g., in correctional facilities, detoxification programs and employment/skills training programs), this project established a peer educators' bureau. Among the positive outcomes reported to date are a growth in peer workers' confidence and sense of effectiveness (springing from their experience as prevention educators) and an increased sense of control over their own sexual health. Through their involvement, these peer workers have not only expanded their skills, but as a result of being introduced to new concepts – for example, the determinants of health and how these are linked to HIV/AIDS and HCV – they have also enhanced their working knowledge of broader health issues. In another project in Manitoba, inner-city youth were recruited to produce and perform in a play and develop a video aimed at educating their peers. Given a voice to speak out in this way, the young workers reportedly experienced positive effects, including "a sense of importance" related to being the ones responsible for getting the message across to their peers. They also had opportunities to broaden their life experience – for example, by attending a theatre production and meeting real actors.

Some projects wished that they had involved client populations more fully, or sooner. One project, reviewing what could have been done differently, suggested that there should have been more input from lower-income groups. On the other hand, another project report suggests that there can be disadvantages in relying too heavily on non-paid staff. It stated that the project was slowed down because "all those involved in the chapter are volunteers." A number of projects also pointed to gaps between the ideal and the reality of client/community participation, noting that at times peer workers can be hard to recruit, challenging to work with, and easy to lose.

One Alberta project, although eager to involve peers through a "natural helpers group", found this difficult because of the small population from which helpers might be drawn, and their ever-changing life circumstances. Its report noted that whenever potential helpers (injection drug users) entered treatment programs, left the community, or were incarcerated or drawn into personal or family crisis, the pool of possible recruits shrank even further. A theatre project in Manitoba commented that it was "hard to hold a group of at risk youth together over a year-long process", noting that the group was challenging to work with in terms of discipline to conduct the work needed (e.g., concentrating, learning lines between rehearsals). It concluded: "These are the types of challenges that can arise when working with street people, drug users, people experiencing poverty".

A project to develop a comprehensive model for providing hepatitis C services to Calgary's homeless remarked in its report on the difficulty of recruiting hepatitis C peer trainees (for support work and identification of the barriers to testing, treatment and support). Another project report hinted that societal stigma might be at the root of peers' hesitancy to get involved, and two others questioned whether compensating peer workers might boost participation. However, another project report noted that when people's health is compromised, cash incentives may not be enough. In its words, "many clients want to volunteer, but they quickly find they lack the energy to continue."

Acknowledging that there will always be some clients who are too ill to volunteer, what are the critical ingredients of successful peer involvement? A Manitoba project may have found part of the answer. Noting that "the most successful aspect of the project was the peer advisory group who formed the heart of the project", the report began by outlining the contribution made by group members. They had "kept the project relevant, made content decisions, provided unique perspectives and information, and were motivated by the true desire to reduce harm" in the injection drug-using community. The report then unveiled the formula for that success: group members already had some formal experience working on the issues, as well as informal knowledge; the group rules were posted; roles and expectations were clear; participants were paid $20 for their involvement, provided with dinner, and compensated for child care and transportation; they acquired new knowledge/skills – not just about hepatitis C, but also about communication and the process of creating a pamphlet – and were able to use what they had learned. When the project was over, "they all believed they had contributed meaningfully and were proud of the product".

c) Attention to Detail

Lesson:

Careful preparation and attention to small tasks do not stall the process – they facilitate it.

Scattered throughout the project reports are references to so-called "administrative details." Although sometimes irksome, these can, if overlooked, undermine even the most brilliantly conceived initiative – as one or two projects found when they encountered problems after glossing over fundamental requirements. By bravely sharing their experiences, such groups can help other project organizers – present and prospective – to avoid some of the same traps.

Perhaps the most common regret was that of not having clearly established the roles and responsibilities of everyone involved from the outset. As one group noted, project goals, target areas, the committee's role, individual roles, and the responsibilities of the chair and project manager – including signing authority – should have been discussed and agreed before the project began.

Another project reported that the lines of authority had not been made clear to the project coordinator, who "did not know what was expected of her". Such basic building blocks, if improperly laid, can make it difficult to determine where the roots lie when problems arise later. In this example, the lack of clarity meant that two questions had to be asked when things started to go wrong: Were the project coordinator's skills and motivation adequate? Or, was the co-ordinator inadequately supervised?

One report, from a project that had collapsed, revealed the pitfalls of inadequate record-keeping. In this initiative "No minutes were kept of project team meetings, making it impossible to determine what really led to the breakdown of the project as originally conceived". The project organizers recommended that in future, "minutes of all committee, working group and/or management team meetings should be recorded, kept on file, and distributed to all appropriate parties." Further, all policies, procedures, terms of reference and instructions to staff should be kept on record.

It is all too easy to overlook the obvious. One project, having neglected to budget for the necessary travel, was unable to implement the activities it had planned for outlying communities. Another project in Ontario noted that "geographical distances made travel difficult in winter".

It can be tempting to plunge headlong into a project, forgetting the preliminary details. However, as one group noted in its report, it is important to spend time laying the groundwork with other potential collaborators. This particular group introduced its project to organizations by means of introductory telephone calls and e-mails before attempting to set up meetings with them, thereby respecting their need for advance notice and adequate preliminary information. The project organizers felt that this seemingly small activity was so important that it was worth identifying under the heading "What Worked".

Two other projects came to regret having started without adequate preparation. An AIDS-related group felt that, with hindsight, it should have spent more time familiarizing staff with hepatitis C issues. Another project group found that "longer planning" was required in order to carry out a needs assessment and do capacity-building. In a similar vein, a third group expressed surprise at the amount of time consumed by project "set-up".

Because this had not been foreseen, the impression had been given that the project was not making any progress.

Some projects discovered what may seem elementary – namely, that communities often do not like it when "outsiders" coordinate their projects. However, recruiting contact persons and/or staff locally may not be enough. As other projects observed, in order to gain trust and confidence project workers must be known within the community and/or have had prior involvement with it.

d) A Whole-Person Approach

Lesson:

When designing and implementing the various facets of a project, it is important not to lose sight of the whole person. Overlooking critical contextual factors and/or client "life circumstances" may imperil the success of the initiative.

On many occasions, disappointing results led project organizers to reflect on whether they had adopted too narrow an approach. Given the known associations between hepatitis C and socio-cultural factors, a broad perspective – one that looks not just at people's behaviours but their life situations as a whole – can yield important clues as to what is likely to work and what is not.

For example, when women inmates failed to turn up for the educational events run by one project, organizers were forced to recognize that "[incarcerated] women, who are required to spend all day in programs, are not willing to spend evenings attending another program". Inner-city projects provided additional illustrations: in one instance, homeless hepatitis C-infected persons could not access government social assistance, since the system required that applicants have a telephone and a mailing address. In another project, organizers planning to promote hepatitis C testing among homeless Francophones discovered that in order to be tested people first need identification and health insurance cards. This formal type of documentation is something that most transient populations do not have. In this case, the project workers concentrated on building relationships of trust with their clients through helping them complete the forms needed to obtain identification to access various types of assistance. They reasoned that in the long run this would open the way to improved health for their clients, and enable them to learn more about hepatitis C.

Another project to educate youth about hepatitis C risks found that providing them with the information was not enough. These youth had no interest in health issues that might affect them at some future date. Indeed, they hardly cared to know what else might be wrong with them when they already had so many physical, psychological and social problems. This was a

rational response, given the reality of their lives. The lack of housing and other basic necessities in the lives of these youths likely contributed to their "survival" focus.

Further illustrating the need for a more holistic approach was another project involving street youth. According to the project report, these youth also found it difficult to look ahead to a future time when they might be ill. Some actually said they did not even know if they would be alive in a few years' time. This contrasts sharply with the sense of "invulnerability" and "immortality" often found in middle-class youth. It would appear that their homelessness, rather than their age, determined their response. In yet another project in which street youth showed negative attitudes to health issues, project organizers came to understand that their lives were "too precarious, unstable and lacking in social structure and support for them to be concerned with physical health issues."

The phrase 'whole-person approach' has an attractive, logical ring to it, but as one project report acknowledged, many stakeholders view it as "good in theory, but not in practice". Even so, one group reportedly managed to "gain trust and relevancy in the population" by "approaching the work with attention to the whole person". This meant helping clients in "their daily struggle for survival", working with them on their transportation, housing and addiction issues, and facilitating access to medical treatment. The project report suggested that, at least from the perspective of this client population, workers who cannot be of immediate practical help are considered virtually useless.

No program can change people unless it is accessible to them. In Vancouver, a four-month bus strike led to a large drop-off in participation in a peer education project. As the report observed, "youth do not have access to cab fare, nor other vehicles – it was already a challenge to get groceries and medications, far less attending an evening discussion group, despite their expressed wish to do so".

Project planners and workers need to be familiar with factors in their clients' lives that affect their ability to participate. The Vancouver project report noted, for example, that client attendance traditionally dropped off in the summer months because of the warmer weather, seasonal job opportunities, and the vacation schedules of the various professionals providing support services.

Even when clients' life situations have been taken into consideration, success is not guaranteed. Groups working with street populations point to the fragility of any apparent project achievements, given their reliance on "relationships and connections [that are] hard to maintain with persons who have so few attachments in their lives." Sometimes the truth is that "the totality of [clients'] conditions of life cannot easily be improved".

One funded project suggested that for youth to be healthy, they need hope. From the service providers' side, this means "supporting positive choices, by providing positive alternatives for recreation, employment and education." Another project urged the appropriate levels of government to focus more on addressing people's basic housing, health, employment, and education/training needs. A third project suggested that when clients are experiencing problems in so many areas of their lives, the best way to have a positive effect

on their health is to take a "whole-person approach" to *all* dealings with them – be it providing formal or informal assistance, support or follow-up services and whether the issue is addiction, shelter, nutrition, violence or the justice system.

It can be tempting for health and social service workers to assume that everyone with a problem needs outside help. One regional project illustrated the importance of understanding the community culture, which provides the backdrop to people's lives and informs their actions and interactions. In this instance, project organizers had overestimated the numbers potentially interested in joining a support group. As the report noted: "In remote communities, such as those targeted in this project, many learn to cope on their own, with family help, without seeking group support. They prefer to remain private." A local priority needs assessment would likely have revealed this.

7. Best Practices

"What worked?" Thirty-seven reports identified aspects of their projects that they regarded as positive accomplishments. For the most part these successes were process-oriented, although some projects listed outputs/products that they felt had worked well.

7.1 Process

Responses in this category fell broadly into two groupings:

- factors that helped smooth the way for ***project organizers*** (administrative tools, approaches and mechanisms, etc);
- factors that contributed to project success mainly from a ***client*** perspective (content/format, client-sensitive setting, delivery mode, etc).

It should be noted that a factor that is helpful to clients may also smooth the way for project organizers, but it may not. The groupings below seek to show where the positive effect of any given practice/approach was *principally* experienced – i.e., at the *organizer* or the *client* level.

Factors that mainly helped to smooth the way for ***project organizers*** included:

- collaboration (e.g., team-building, committee approach, use of pre-existing community connections, the range of community partners involved);
- the participation of a wide variety of stakeholders in project advisory committees (e.g., corrections personnel);
- partnerships (e.g., the partnership between one project group and a provincial pharmacists' association improved the quality of the resource, boosted its distribution and enabled the project to go province-wide);

- peer involvement;
- use of a whole-person approach;
- physician participation in educational sessions (e.g., gastroenterologists and hepatologists, leading to increased attendance);
- newspaper advertisements, which, although sometimes costly, generated calls for information;
- press articles and the use of media interviews to raise awareness;
- preliminary meetings held with prison inmates (which promoted the project and facilitated inmates' involvement in developing educational tools/strategies);
- [an NGO's] prior knowledge and experience of inmate culture and prison issues (which aided in developing a successful strategy for client involvement – in this instance, a tattoo art contest);
- the ability of an outreach staff team to engender trust among clients and make positive connections;
- a harm-reduction approach (with street populations);
- reaching out to priority populations in a discreet low-profile manner (reducing clients' fear of stigma);
- the supportive attitude of an NGO Board of Directors to the needs of a youth theatre troupe (attending rehearsals, listening to the youth and ensuring that board policy decisions reflected the needs they expressed);
- ongoing professional development for paid and volunteer staff (attendance at conferences, courses, workshops) as a means of strengthening project capacity;
- a flexible approach to programming (enabling opportunities to be fully exploited);
- the solicitation of regular community feedback (allowing projects to stay responsive to changing community needs).

Factors that contributed to project success more from a ***client*** standpoint included:

- participation by spouses/companions in a weekend conference (and funding their transport, meals and accommodation);
- individualized approaches (including private meetings and telephone contact, which allowed clients to steer the meeting and "unload" their personal worries and concerns);
- suppers and film discussions, which were enjoyed by youth;
- the understanding of clients' circumstances (as demonstrated by the use of a film character with whom they could readily identify);

- the hiring of a hepatitis C-infected project coordinator who could share her own personal experiences with others;
- the provision of an informal anonymous comment book for use by community groups (which led to the expansion/development of resources to include hepatitis C, co-infection and needle-use issues).

7.2 Products

Project reports also pointed to various outputs that were well received by various client populations. These included:

- skits presented by youth for youth in Atlantic Canada (gauged by the subsequent requests for performances received from local high schools);
- a game show-like tool that peer health educators in Vancouver used for education/harm reduction purposes. It reportedly helped peers to both stay on top of developments in youth sexual health and assess the information needs of specific groups of youth;
- a pamphlet produced for the injection drug-using population (prescription and non-prescription), acclaimed for its clarity, accuracy and attractive lay-out;
- "prevention kits" and other educational resources used to educate and raise hepatitis C awareness among inmates in a Quebec detention centre.

7.3 Documenting and Sharing

As more projects are completed, it will be useful to examine successful processes and products in order to identify common elements and determine whether they can be adapted to other settings/audiences. Meanwhile, project organizers are being encouraged to carefully document their projects, including any factors that may have influenced their outcomes, and to share useful information with the wider hepatitis C community.

With this in mind, in 2001 a number of community groups were invited to make presentations on their projects at a session on "Innovative Community Projects" at the 1st Canadian Conference on Hepatitis C in Montreal. The conference provided an opportunity to publicize the efforts and accomplishments of the many groups who provide hepatitis C prevention, education and support services to communities across the country. This proved to be an effective and popular means of disseminating information about models and tools and several presenters reported that their work had generated considerable interest. Groups should be encouraged to continue this kind of dialogue, which enables them to exchange experiences, borrow ideas and approaches, and openly explore what went right or wrong.

8. Future Directions

Information on future plans, needs and directions was noticeably scarce in the reports as a whole, possibly because a large number of the projects were still in progress at report time. Even so, not all of the completed projects identified well-developed future plans. The following observations are drawn from the reports that did attempt to look forward, whether in specific or general terms, and should be considered in conjunction with Section 6. ("Lessons Learned").

8.1 Rising Demand for Prevention Education

Many projects made a plea for the allocation of more resources to hepatitis C preventive education. Using strong terminology ("overwhelming demand", "huge lack of awareness") they called attention to what they saw as a widespread lack of knowledge about hepatitis C in populations at risk, and to the consequent need for ongoing hepatitis C awareness/prevention programs on the street, in correctional institutions and ethno cultural communities/agencies, and among high-school and university students. One project noted that many school teachers and administrative staff are themselves misinformed about hepatitis C and HIV/AIDS.

In its report, a Quebec project (a training initiative) noted that there were waiting lists for worker education in several parts of the province. Another report noted that although an estimated 10,000 Manitobans were hepatitis C-positive, only 3,500 had so far been identified. By this count, 6,500 infected persons were still to be located and tested (often in remote areas, with implications for resource allocations). This signals a large hidden problem, not confined to one part of the country, in which those who are infected but unaware of it could put at risk others who themselves may lack the information they need to protect themselves. Moreover, many agencies responsible for education are also attempting to provide services and support, intensifying the pressure on their resources. Calling for additional support services, especially for co-infected persons, one project report warned: "There are simply not enough community agencies funded to provide hepatitis C services and education, especially for inner-city populations".

8.2 Support and follow-up for clients and families

Two of the program's *guiding principles* are relevant here. They testify to the importance, first, of meeting the needs and priorities of people who have hepatitis C, those at risk of becoming infected and others closely affected (such as family and caregivers) and second, of finding practical, immediate ways of making people's lives better. As more cases of hepatitis C are identified, such needs will only increase.

Some project reports urged that more support be made available to persons testing positive for hepatitis C, especially inner-city youth, for whom follow-up and treatment are major

concerns. Project experience in the second funding year suggests that it may be unrealistic to expect support groups, which are a key mechanism for helping the newly diagnosed and their social networks, to become immediately self-sustaining. One project recommended that community groups and their workers remain in close contact with fledgling support groups, providing periodic help with organizational and development issues. An assortment of other strategies were proposed, including: connecting persons who wished to avoid public identification with persons in similar situations; expanding the language capabilities of support group facilitators and telephone networks; continually updating the information available to support groups, enabling them to stay in touch with new developments; and training more volunteers to provide support and follow-up services.

Reports highlighted the need for increased resources for psycho-social support and education services (to deal with clients' anger, isolation and confidentiality concerns), including one-on-one counselling. The latter approach seemed to work well with some individuals as a first step, prior to group work. Bearing this out, several clients who had received intensive one-on-one support ended up volunteering time to the project, and others were even able to return to paid employment.

Project reports suggested various means of enhancing one-on-one support, from acquiring a pager for round-the-clock individual support to including relevant counselling expertise on the project team.

8.3 Physician Education

In the words of one project report, a key to future success will be "vigilance towards building inroads with the medical community". Notwithstanding their key position as gatekeepers, as one project group suggested "family physicians need to be more educated about hepatitis in all its forms (A, B and C)". It was surmised that additional information would facilitate physician[10] involvement in hepatitis C prevention and education efforts. Yet, except for one project in Atlantic Canada that described its Continuing Medical Education Seminar as a "major accomplishment", project groups found it difficult to attract medical professionals to their educational sessions, even though special efforts were made to accommodate physician needs. To try to remedy this situation, one group noted that it had "begun engaging the medical community in a more direct manner", by calling doctors directly to describe their project objectives and activities. Another project report recommended that a specific plan be developed to gain physician collaboration by organizing a specially tailored seminar.

10 With three notable exceptions: physician specialists with an interest in liver disease, such as hepatologists and gastro-enterologists; public health physicians; and family physicians working in community health centre settings.

8.4 Training for Corrections Personnel

While some projects established productive relations with corrections officials, many others pointed to the need for corrections staff to be better educated about hepatitis C. There were also specific suggestions aimed at increasing the role of corrections personnel in prevention and education. For example, one group recommended that the health/safety staff of correctional institutions should be included in the local hepatitis C network, and another group proposed greater ongoing co-operation with corrections staff in educating inmates about hepatitis C.

Some particularly disheartening experiences were reported by another group which undertook its project in a detention centre. Certain prison guards and staff had openly disparaged the project and refused to participate. In fact, these staff members had claimed that far from helping, the project activities were contributing to disorder in the establishment. In its report, the project group suggested that considerable work would be needed with corrections staff to remedy these types of educational and attitudinal deficits. Any such effort should take into account that (as this report commented) corrections personnel may feel caught between their "harsh" role as enforcers of order and discipline, and the more caring role of helping inmates protect their health.

8.5 Diversifying Approaches

In their information-gathering efforts (before commencing their projects) groups demonstrated a clear appreciation of the need to tailor their activities to audience needs. As mentioned earlier, a wide variety of forums/settings and approaches were used for consulting different groups, with marked success in many instances.

Project groups generally acknowledged that no one publication or tool can meet the needs of everyone in a community. In their reports, they emphasized that resources must seek to reflect clients' different needs and circumstances, varying in content, format and/or emphasis according to the clientele's cultural background, socio-economic status and/or other characteristics.

Audience diversity also implies a need for more varied approaches to service delivery and communication channels. Project reports reflected on the importance of ensuring that resources actually reached their audiences as intended. Many possible dissemination channels were identified, including public health nurses, community and conference presentations (possibly on a cost-recovery basis), and articles in publications read by service providers and other priority groups. One project report commented that people in the middle classes can sometimes be more difficult to access than members of traditionally hard to reach groups, since the former are less likely to belong to effective hepatitis C networks (as do street people, for example).

Broadening the partnerships and networks involved in project planning and delivery was identified as a good way of addressing client diversity. Many project reports also pointed to

the need to further develop/expand hepatitis C networks in rural and geographically remote communities.

8.6 Determining the Effectiveness of Interventions

One of the Program's guiding principles highlights the need to track results and performance, in order to continue learning and improving. To achieve this, project groups must be able to assess the effectiveness of their initiatives (a skill implied in the term "enhancing community capacity"). With this in mind, the Program devoted considerable effort in the first two funding years to developing simple, realistic approaches to evaluating project success – approaches with the potential to yield useful information without unduly burdening project staff. It should be noted that most year two projects had not yet integrated the relevant evaluation tools into their reporting processes.

Project groups faced many other evaluation challenges. For example, although some of the results they achieved were quite tangible (e.g., outputs such as training sessions, pamphlets, plays, etc), the effectiveness of these outputs may remain in question. Do they actually work? And, if they appear to work, is the result necessarily attributable to the particular output? When many influences are at play – for example, press articles, radio call-in shows, friends sharing knowledge – is there any valid basis for attributing positive results solely to project activities? At best, the project is but one of many factors, known and unknown, working in concert to affect the client population. Furthermore, meaningful results may only be observable over time. Succumbing to pressure to wrap things up quickly, project groups can be tempted to make definitive claims/statements too early on.

On occasion, a project group may need to re-articulate its objectives as the initiative unfolds – perhaps conditions have shifted or the initial goals/objectives were simply too ambitious. (A three-month, $5,000 project is unlikely to result in major changes in hepatitis C incidence rates in a large city.) While learning on the job is important and valuable, it can present challenges (since revised goals and objectives call for revised evaluation plans).

Although only a few groups were in a position to submit formal evaluation reports, several commented on evaluation issues. For example, there were those who called for a greater focus on evaluation, including a more systematic collection of quantitative and qualitative data for evaluation purposes. One project report pointed to the need for yet further follow-up with clients, to determine whether an intervention had made any *long-term* difference in their health practices. However, it noted that for a "rigorous regional evaluation" to make sense, at least three years of secure project funding would be needed. This would allow interventions to build progressively on each other. Still another project planned to survey the extent to which the information in its resource had actually been *used* by readers – i.e., had their initially positive reactions to the information translated into behaviour change? This is an important and necessary question to ask. Moreover, it needs to be asked of clients as well as workers who may have attended training or received tools, such as manuals, to help them conduct preventive or educational interventions.

In one project, trainees (street workers) who were questioned about the impacts of their training identified several areas in which they had taken follow-up action (testing, training, vaccination against other forms of hepatitis, research, communication and referrals). In another initiative, more than one-third of the clients attending a presentation said they planned to go for hepatitis C testing as a result of what they had learned, and one-half intended to join a support group.

Some project groups stressed the long-term nature of the challenge of achieving changes in client behaviours and attitudes, especially among youth. One project report commented that even when youth know "the facts", getting the information to "sink in to the point where it influences their behaviour" can be a "lengthy and arduous" process. It concluded: "The information needs to be repeated many times before it impacts on their actions."

8.7 Sustainability

The Program's guiding principles emphasize the importance of undertaking initiatives that have staying power. Groups were expressly invited to comment on the potential sustainability of their projects. However, only a few did so. This is not surprising since most of the initiatives were still in their early stages. (The Hepatitis C Prevention, Support and Research Program itself was not much more than two years old at the time.)

Among those groups that did comment, some identified volunteers as the way to the future. One organization with a national profile saw the recruitment of volunteer program coordinators in three locations as the answer. With such coordinators in place, community knowledge and understanding of hepatitis C would grow and more gateways to information would open up locally. In time this might lead to the emergence of new volunteer chapters. Another group committed itself to developing stronger fundraising strategies to aid with expansion and sustainability.

The "great community success" of its theatre project inspired one group and its Board members to pledge their continued involvement once funding ended. They undertook to identify and generate whatever additional financial, community and personal resources might be needed. Another group promised to make its demonstration project materials available as a template to any interested group. If national interest/sponsorship from larger agencies and/or governments were not forthcoming, this group would "attempt to find a way to continue the project, by begging if necessary".

9. Conclusion

Hepatitis C presents communities in Canada with enormous, multifaceted challenges. From the perspective of the hepatitis C community, there is an *awareness* issue: those who are at risk may know little about either the virus and its transmission or the disease and its symptoms/progression. Further, those who are already infected may not even be aware of this fact. There is also a *prevention* issue: that of identifying and modifying the behaviours and circumstances that increase the risk of hepatitis C infection. Once people test positive for hepatitis C, or the symptoms of hepatitis C begin to appear there may also be a *support* issue. For example, immediate, practical assistance may be needed to deal with *physical* problems such as nausea and fatigue, *social* problems such as isolation and stigma, *economic* problems such as the inability to keep a job and high medication costs, and *emotional* issues such as fear and shame.

Overarching all of these concerns is the fact that hepatitis C tends to thrive in conditions of poverty, homelessness and despair. This knowledge forms the backdrop for the work of many communities, whose tasks include identifying and locating groups at risk, meeting them "where they are at" and finding sensitive and appropriate ways to address their needs. At the same time, they must develop the resources, skills, systems and infrastructures needed to carry out these tasks capably. Finally, they must monitor the effectiveness of their approaches and keep abreast of new developments and research.

Viewed in this light, progress at the community level in year two has been solid, useful and encouraging. The increase in funded projects multiplied opportunities to heighten community hepatitis C awareness/knowledge and provided new chances for innovation in service approaches and educational tools, especially in urban Canada. It also led to improved skills and capacities on the frontline. At the same time, project experience in 2000-2001 helped to highlight the need for greater *clarity* in some areas (e.g., the meaning of "partner"). It also pointed to several other areas in need of closer *attention* including: the hepatitis C needs of rural and remote populations; reporting and evaluation requirements; the role of poverty in the spread of hepatitis C and the importance of building a "determinants-of-health perspective" into all stages of community initiatives, from planning through to evaluation.

Overall, a firm foundation has been laid for curbing hepatitis C infection rates and ameliorating the effects of hepatitis C on various population subgroups, their families and social networks. It has been hard work, and the results have been incremental rather than spectacular. But the importance of these early expenditures of resources and effort lies principally in their ability to generate guidance for the future. And, as this report shows, useful lessons have indeed been forthcoming – lessons that, if studied carefully, can help point a clearer way forward.